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African Americans' opinions about human-genetics research

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ABSTRACT

BACKGROUND. Research on attitudes toward genetics and medicine registers skepticism among minority communities, but the reasons for this skepticism are not well known. In the past, studies linked mistrust of the medical system to historical ethics violations involving minority groups and to suspicions about ideological premise and political intent.

METHODS. To assess public knowledge, attitudes, and behavior regarding human-genetics research, we surveyed 858 Americans onsite in four community settings or online in a geographically nonspecific manner.

RESULTS. Compared to participants as a whole, African Americans were significantly more likely to believe that clinical trials might be dangerous and that the federal government knowingly conducted unethical research, including studies in which risky vaccines were administered to prison populations. However, African Americans were also significantly more likely to believe that the federal government worked to prevent environmental exposure to toxicants harmful to people with genetic vulnerabilities.

CONCLUSIONS. Our data suggest that most Americans trust government to act ethically in sponsoring and conducting research, including genetics research, but that African Americans are particularly likely to see government as powerfully protective in some settings yet selectively disingenuous in others.

The historical mistreatment of minority groups in government-funded health programs remains an important concern for contemporary genetics researchers and public officials. In this respect, The Tuskegee Study of Untreated Syphilis in the Negro

Male, conducted from 1932 to 1972 by the United States Public Health Service in cooperation with the Tuskegee Institute, is especially evocative. African American men with syphilis were intentionally left untreated and were deliberately misled for decades, ostensibly so that researchers could observe the natural history of a disease whose curative management

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improved drastically — for everyone *else* — during the life of the study. The Tuskegee Study began well within living memory of slavery and claims of brutal experimentation on a captive population; it began, as well, just as African Americans' fear of hospitals was beginning to fade.¹

In 1972, when the Tuskegee Study was shut down in the glare of press exposure, the Sickle Cell Anemia Control Act was passed. This measure, for which many African-American activists campaigned, was entirely different in its intent: optimization of treatment through early discovery of cases and assistance to decision-making through counseling. The Act, too, though, became a target for ethical censure. Since it supported routine screening of newborns for sickle hemoglobinopathies, the Act led to many families being alerted to the sickle-trait status of babies and young women and, by implication if not initially by test, young men. Employment and insurance discrimination followed, and most of this was medically irrational as well as unfair. Ultimately, many states either required screening or required explicit refusal to avoid it. Recently, African-American sociologists and geneticists have expressed concern that the motivations underlying federal and state genetic-screening initiatives might be eugenic.^{2,3,4}

Governmental involvement in human-genetics research proceeds in the shadow of this history, and other histories much to the same effect, all posing difficult questions for and about minority groups.⁵ When the Human Genome Project was launched a decade ago, African Americans sought to prevent ethical abuses from recurring. One group released a manifesto demanding “full inclusion in any world survey of human genomic diversity”; warning against extrapolation from *samples* of African Americans to *all* African Americans; recommending a national review panel to monitor the project; advocating community involvement throughout; asking that priority be given “to studies that examine the linkage of African Americans to continental Africans and other Africans of various diasporas”; and, finally, pushing for results to be used directly to improve health and education in African-American communities.⁶

Genetics research poses problems for the concept of race because findings may be used to support a striking array of positive and negative propositions, along both similarity-dissimilarity and inferiority-superiority spec-

tra, and each proposition has its consequences for public perceptions and public policy. Putative links between genes and race are now so controversial that some researchers are asking why the National Institutes of Health (NIH) continues to fund medical research that uses race categories when race is, to a large degree, a sociocultural designation.⁷

We explore the contradictory experiences that have made up African American's unique position on human-genetics research. In particular, we explored why African Americans, in agreement with other Americans, continue to support human-genetics research despite historical abuses and ongoing discrimination. First, we review group-to-group similarities and differences in attitudes about race and outline the particular concerns of African Americans in an age of medical-genetic advancement. Then we present survey data illuminating this topic.

Attitudes toward medicine and genetics

Collective memory of abuse poses one set of problems for research. The status of minority health in the United States poses another. While 1 in 10 European Americans lacks health insurance, 1 in 4 African and Asian Americans and 1 in 3 Hispanic Americans have no coverage,^{8, 9} and being uninsured or underinsured typically is explained by being unemployed or underemployed — or by being employed at a compensation level too low to allow conversion of individual wages to group benefits.

Nonetheless, the range of opinions African Americans exhibit on government and research is wide. One explanation might relate to increasing visibility of genetics in public and popular discussion. Lay audiences report increased knowledge of and trust in genetics technology. The National Science Foundation (NSF) has reported that the percentage of Americans agreeing that “the benefits of science are greater than any harmful effects” rose from 57 percent in 1979 to 72 percent in 2001.¹⁰ Similarly, suspicion that employers or insurance companies might use genetic information to discriminate against employees *decreased* from 55–60 percent in 1995 to 20 percent in 2000.^{11, 12, 13} Yet, opinion polls can obscure minority positions; if genetics research were to benefit everyone, as the Human Genome Project has promised, good policy would recognize the “exclusionary aims of consensus and

unity.”¹⁴ Good policy would be attentive to the concerns of minorities.

Survey and opinion research has addressed group attitudes on organ donation, clinical trials, physician trust, credibility of the institution of medicine, genetic technology, causes of illness, and, more recently, race-targeted pharmacogenomics. Several group-to-group differences have emerged.^{15, 16} Compared to European Americans, a higher percentage of African Americans who might consider organ donation perceive the organ-distribution system to be unfair and believe that physicians would be comparatively unlikely to save them if donation went awry.^{15, 17} On a similar measure of physician trust, surveys on clinical trials have shown that just one-quarter of African-American women surveyed indicated that they felt clinical cancer research was ethical, a finding that may explain low participation rates.¹⁶ Some researchers have noted difficulties in attracting African American participants to university campuses just for survey research, highlighting a problem extending across the institutions of medicine and science to other investigational disciplines.¹⁸

Still, groups' distrust of institutions is not monolithic. In another assessment, African Americans were more likely to trust employers with genetic information than were European Americans.¹⁹ Focus group research has underscored difficulties in extracting any coherent “group opinion” about medicine, genetics, and government. When asked to rank the relative importance of social, environmental, and physical factors in susceptibility to disease, African and European Americans responded similarly,¹⁸ and both groups were highly suspicious of race-targeted pharmacogenomics and were reluctant to believe that such “ethnic” pharmaceuticals would be effective.²⁰

Nonetheless, in a survey of 886 adults, Furr found that African Americans were more likely than European Americans to say that genetics was harmful for society.²¹ Furr and Seger have postulated that for African Americans, “genetic technology may carry political baggage that differs from other health and non-health technologies.”²² This baggage, or its relationship to group-characteristic suspicion, has not confidently been identified. In a recent National Health and Examination Survey, African American participants were less likely than others to allow their DNA to be stored for future research, even when anonymity and privacy were “guaranteed.”²³ In explaining why a majority of

surveyed African Americans declined organ donation, the authors cited “a high rate of medical mistrust” anchored in “a deep-rooted and well-justified mistrust of physicians and hospitals.”²⁴ Likewise, Beeson and Duster's recent interviews of family members of African-American men and women who had a relative with sickle-cell disease found their suspicion of the US public-health system went “far beyond occasional references to the Tuskegee syphilis study.” Participants told stories “saturated with references to medicine as an instrument of domination and control.” The interview subjects also expressed disbelief that medical advances would help their communities.⁴

To explore these attitudes further, we composed and administered survey to an economically, racially, and educationally diverse sample approximating the characteristics of the communities represented.

Methods

We surveyed participants of an omnibus study²⁴ designed to assess public knowledge, attitudes, and behavior regarding human-genetics research in the United States.

Participants were asked to respond to a survey assessing knowledge, attitudes, and behaviors associated with human genetics. The survey items evolved from the content analysis of 17 focus groups conducted with African-American and European-American males and females between the ages of 18 and 40 years.²⁵ Focus-group discussions in this earlier work centered on the role of genes in human health and disease, in growth and development, in attainment of final height and maintenance of desired weight, and in the expression of talents and mental abilities; the role of genes was also compared to the health-and-disease role of physical environment, social environment, and personal choice. From these discussions, 158 unique statements about the influence of genes on human health were written, with items including statements about illness susceptibility and severity associated with one's genes; about self- and response-efficacy associated with health behavior, decision-making, and genes; about knowledge; and about related attitudes. Additionally, the following scales were included as part of the survey for purposes of measurement validation: extrinsic-intrinsic religiosity,²⁶ health locus of control,²⁷ racial identity, and fatalism.²⁸

Table 1. African-American and European-American level of agreement with statements about human-genetics research.

Survey statement	Racialized grouping N = 743	Mean (SD) [1–5 scale]	t-value
Research in genetics is a wise use of tax dollars	White (n = 470) Black (n = 273)	3.54 (.889) 3.57 (.987)	–0.388
Clinical trials can harm human genes	White (n = 470) Black (n = 273)	2.79** (.884) 2.96 (.967)	–2.48
The federal government has done genetic testing on prison populations without their consent	White (n = 470) Black (n = 273)	3.08* (.888) 3.23 (.939)	–2.09
I would be willing to participate in research about genetics over the internet	White (n = 470) Black (n = 273)	3.00 (1.10) 2.93 (1.09)	0.865
The federal government puts things in vaccinations that harm human genes	White (n = 470) Black (n = 273)	2.44** (.789) 2.85 (.951)	–6.30
The federal government supports a healthy environment to protect human genes	White (n = 470) Black (n = 273)	2.74* (.857) 2.90 (.972)	–2.29
Conservatism versus liberalism	White (n = 470) Black (n = 273)	2.91 (1.16) 2.94 (1.13)	–.271

* $p < 0.05$ and ** $p < 0.01$ for comparisons of African Americans and European Americans.

To consider possible differences between African American and European American responses on items related to genetic research and government, independent sample t-tests were conducted. Additionally, the possible contribution of education level, number of children, political liberalism, and use of the health care system as represented by last visit to a physician were used in analyses of covariance conducted as 2-by-2 models with African-American and European-American and female-male models. Finally, bivariate correlation coefficients were computed between participant scores for religiosity and locus of control on attitudes to test for relation to political attitudes.

Results

We collected data from 858 survey participants in four community settings: (a) a southeastern town located near a large land-grant university; (b) a southeastern metropolitan city; (c) a northeastern town located near a large state university; and (d) a northeastern metropolitan city. Southern participants consti-

tuted 60 percent of the sample ($n = 512$), and northern participants 34 percent ($n = 292$). An online version of the survey was completed in a geographically non-specific manner by 7 percent of participants ($n = 54$). At the southeastern locations, researchers collected data at a health fair and an airport and at restaurants, churches, retailers, barbershops, beauty parlors, and laundromats ($n = 397$), as well as at a university ($n = 115$). At the northeastern locations, researchers collected data at a train station, bus station, outlet mall, and business office ($n = 191$), as well as at a large land grant university ($n = 101$). Survey administration began in January 2001 and ended in June 2001.

339 participants were males, 482 females; 37 did not report their sex. Various ethnic and racial backgrounds were represented: 62 Asian Americans, 23 Hispanic Americans, 273 African Americans, 470 European Americans, 26 others, and 4 unreported. Age ranged from 18 to 73 years, with mean 29.5 and standard deviation 10.1; for African Americans these measures were 32.4 and 1.3 and for European Americans 28.0 and 9.6, respectively.

Among all participants, 64 percent had no children; 23 percent had either one or two children; and 11 percent had three or more children. Among African Americans, these measures were 45, 37, and 10 percent, respectively; among European Americans, 73, 8, and 9 percent, respectively.

Education levels varied from less than high school in 3 percent, high school graduation in 16 percent, vocational-technical graduation in 4 percent, college attendance without graduation in 24 percent, college attendance with graduation in 30 percent, and graduate-school graduation in 21 percent. For African Americans, mean education attainment was tenth grade, while for European Americans eleventh grade. 19 percent of the entire sample recalled some college-level exposure to genetics concepts.

87 percent of the entire sample had health insurance of some sort. Of African Americans, 82 percent did, and 83 percent had visited a physician within the previous 18 months. Of European Americans, these measures were 91 and 79 percent, respectively.

Results of t-tests are shown in Table 1. African-Americans manifested attitudes in several respects significantly different from European Americans. African Americans were significantly more likely to say that the federal government conducted undesirable genetic

Table 2. Correlations between participant characteristics and attitudes.

	<i>External locus of control</i>	<i>Internal locus of control</i>	<i>Intrinsic religiosity</i>	<i>Extrinsic religiosity</i>	<i>Age in years</i>	<i>Number of children</i>	<i>Highest level of education</i>
Clinical trials can harm human genes	0.112**	0.020	0.062	0.072*	−0.035	−0.024	0.026
Research in genetics is a wise use of tax dollars	−0.033	0.102**	0.006	0.049	0.063	−0.024	0.081*
The federal government puts things in vaccinations that harm human genes	0.158**	−0.027	0.101**	0.121**	0.035	0.120**	−0.038
The federal government supports a healthy environment to protect human genes	0.112**	0.146**	0.058	0.125**	0.003	−0.019	−0.062
The federal government has done genetic testing on prison populations without their consent	0.042	0.001	0.097**	0.049	0.08*	0.079*	0.030
I would be willing to participate in research about genetics over the internet	−0.034	0.036	−0.071*	−0.017	−0.065	−0.086*	0.015

* $p < 0.05$, 2-tailed.

** $p < 0.01$, 2-tailed.

research, including research on prison populations using harmful vaccines. African Americans were also significantly more likely to indicate that clinical trials might be dangerous. However, they were at the same time more likely to see the government as protecting them from environmental exposures associated with genetic damage.

Analysis of covariance revealed no significant effects for education, number of children, age, or political liberalism on attitudes about clinical trials, belief in use of tax dollars for research in genetics, that the federal governments puts thing in vaccinations that harm human genes, or belief that the federal government supports a health environment to protect human genes. Number of children was significantly related to the belief that the federal government had done genetic testing on prison populations without their consent ($F [1,653] = 6.33$, $p = 0.01$). Political liberalism was significantly related ($F [1,637] = 3.91$, $p = .05$) to willingness to participate in research about genetics over the Internet.

Table 2 data suggest that higher scores on an external-locus-of-control scale were related to stronger beliefs that clinical trials could damage human genes and that some of these risky trials were performed by the federal government to test vaccines but that this same government supported environmental protection so as to prevent human-genetic damage.

Intrinsic religiosity, the sense of living in accord with one's spiritual faith, was positively related to belief in governmental misbehavior and negatively related to willingness to participate in genetic research over the Internet. Extrinsic religiosity, participation in the out-

ward and visible signs of organized religion, was positively related to belief that clinical trials could damage human genes, that the federal government adulterated vaccines, and that it protected environmental health. Age and number of children collinearly predicted belief that the federal government conducted genetic testing on prison populations. A greater number of children predicted suspicion about the adulteration of vaccines but also a disinclination to participate in genetic research over the Internet. Finally, level of education predicted support for public investment in genetics research but otherwise was attitudinally neutral.

Discussion

We found broad agreement between African Americans and European Americans on many human-genetics research issues. We also found further support for Furr's and Seeger's assertion that African Americans tended to be more skeptical.²¹ In our survey, they were more likely to believe that government would test vaccinations likely to damage genes, and they were also more likely to agree that prison populations were subjected to genetic testing without consent. Paradoxically, though, African Americans are highly optimistic about the potential of genetics research and willing to fund it.²⁵

Taken as a whole, these data suggest that African Americans see government as a more active agent than do European Americans and are more likely to ascribe *either* blame or credit to its actions. African Americans may be less optimistic about genetic testing, but their expectations for government activity are higher, and so their willingness to fund genetics research is about the

same as that among European Americans. These results suggest an external-locus-of-control effect, in that fate or powerful others — in this case, the federal government — seemed to have more control over one's life than one did oneself. On the other hand, belief in the wisdom of using tax dollars for genetics research and belief in the government's role in supporting a healthy environment were positively related to an internal-locus-of-control effect.

According to our measures, "liberalness" and "conservativeness" explain little here. However, attitudinal self-reports such as these may not be highly reliable. They conflate cultural and economic issues and ask people to estimate where they fall on a continuum. Given social isolation between groups, individuals may estimate their own attitudes with regard to their *own* group, not the national population. Better measures more diversely applied would benefit future investigations.

We began with a hypothesis that suspicion about human-genetics research might be explained in racial terms because of African Americans' cultural memory of research-ethics violations by the federal government. We also surmised that political and ideological factors might predict who would support genetics research — and federal involvement in it. Neither presupposition held. Our findings suggest instead that belief in the power of government is a signal factor in understanding African Americans' support of human-genetics research.

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